

The iParent2Parent Program: Peer Mentoring for Parents of Children with Juvenile Idiopathic Arthritis

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Research Proposal

Rationale

Parents/primary caregiver of children with JIA are an often overlooked but essential member of their child's health care team. They are responsible for managing their child's treatment program, and act as advocates for their child to support positive adaptation to JIA and to learn self-management skills for the disease. This is in the context of managing the financial, logistical, emotional, and social demands of parenting in general. Within pediatric tertiary care centres, peer-support programs for parents of children with JIA are often limited or difficult to access. The iParent2Parent Program aims to fill this gap in services by offering a program of trained parent peer mentors who can provide practical coping advice, foster adaptive problem solving, and provide social support via shared lived experience.

Background and Objectives

Burden of Disease and Challenges to Adaptation

Parent psychosocial health and coping play an important role in a child's positive adaptation following diagnosis of JIA (1). However, parents must meet the everyday demands of their family while simultaneously managing new logistical and emotional demands of their child's medical care (2, 3). Predictably, parents of children diagnosed with JIA are at an increased risk of anxiety and depression, as well as financial hardship (3, 4). Better support for parents of children with JIA is likely to have a positive impact on parents themselves as well as their children.

Peer Support and Peer Mentoring

Peer support in a healthcare context is an explicit form of social support established to provide individuals with emotional, appraisal, and informational support by another person living with a similar condition (5). A systematic review of peer support for parents of children with chronic disabling conditions found that parents benefited from a shared social identity, supporting and learning from experiences of others, and personal growth (6). However, little research exists on parent peer support in JIA and families face numerous barriers to accessing in-person social support specific to JIA. Providing peer support online is an innovative approach to improve the *accessibility* and *acceptability* of peer support programs for parents of children newly diagnosed with JIA.

Preliminary Work

The iParent2Parent Program is based on the collective research and clinical expertise of the team and *patient expressed interest* in a parent peer support program. Both the structure of the iParent2Parent Program and the parent peer mentor training was systematically developed based on: (a) a theoretical framework for peer support interventions in health care contexts (5); evidence of successful parenting interventions in other chronic health populations (6-8); (c) adaption of The iPeer2Peer Program, an established and successful online peer mentor program and peer mentor training program for adolescents and young adults with JIA (9, 10); (d) adaptation of the Cassie and Friends Parent to Parent Support Program (CF-PSP) for parents of children with rheumatic conditions. The CF-PSP has formalized parent mentor training as well as the process of matching parents who would benefit from peer support with another parent who also has a child with a rheumatic condition. The iParent2Parent Program capitalizes on lessons learned from the development of other peer mentoring programs to create an accessible and acceptable program for parents of children newly diagnosed with JIA.

Objectives: To develop a parent peer mentoring program, the iParent2Parent Program, that is

feasible and effective for parents of children living with JIA. This proposal is part of a phased approach to develop online peer mentoring interventions:

Phase 1 (completed): The iParent2Parent Program is based on our previously developed peer mentoring programs: iPeer2Peer Program and CF-PSP (9, 10).

Phase 2 (current proposal): The feasibility of the online iParent2Parent Program for parents of children living with JIA will be evaluated in a pilot randomized controlled trial (RCT).

Phase 3 (future proposal): Results of the pilot RCT will inform the refinement of the iParent2Parent Program and determine the appropriate sample size for a future large-scale RCT comparing the effectiveness of the iParent2Parent Program to a waitlist control group across Canada.

Methods

Specific Aims: This pilot RCT will test the feasibility of the iParent2Parent Program for parents of children diagnosed with JIA. Using implementation outcomes, measures of feasibility will be evaluated and estimates of effect size and variance will be assessed for parent QOL, perceived social support, coping, and parenting stress. Estimates of effect size and variance will inform sample size of a future multisite RCT.

Research Questions:

- I. Primary implementation: Can the iParent2Parent Program be implemented as planned with respects to: (a) what are the accrual and dropout rates? (b) can the program, control, and outcomes measures be deployed as planned (fidelity)? (c) what are parent perceptions regarding program acceptability and satisfaction? and (d) what are the levels of program engagement?
- II. Secondary potential mechanisms of effectiveness: What are the estimates of treatment effect sizes and variance in QOL, perceived social support, coping, and parenting stress, in parents of children diagnosed with JIA who complete the iParent2Parent Program versus a waitlist control group?
- III. Exploratory: Does involvement in the iParent2Parent Program lead to differences in peer mentors' QOL, perceived social support, coping, and parenting stress? What are the perceptions of peer mentors regarding the benefits and challenges of the iParent2Parent Program?

Description of Study Population:

Peer Mentor Criteria.

Inclusion Criteria:

- (a) English-speaking caregiver of a child with JIA
- (b) Nominated by their child's health care team as a good candidate to act in the mentor role, including parents who manage the demands of having a child with JIA, and have low risk factors (no history of mental illness).

Exclusion Criteria:

- (a) Significant cognitive impairment or major co-morbid illness of parent that impedes ability to provide the program (e.g., psychosis, active suicidal ideation, cognitive delays that would impact ability to participate and complete questionnaires)

Note: every effort will be made to recruit a diverse group of parent mentors (e.g., parents of children with various subtypes of JIA, parents who live in rural vs urban settings, various ethnicities).

Mentee Criteria.***Inclusion Criteria:***

- (a) English-speaking caregiver of a child diagnosed with JIA according to ILAR criteria (11) prior to their 18th birthday
- (b) access to computer capable of using free Skype software. *Note:* 85% of Canadian households have high speed Internet availability as of 2010 (12).

Exclusion Criteria:

- (a) Significant cognitive impairment or major co-morbid illness of parent that impedes ability to engage in program (e.g., psychosis, active suicidal ideation, cognitive delays that would impact ability to participate and complete questionnaires)

Study Design:

A waitlist pilot RCT design using central randomization with repeated measures will be used to evaluate the feasibility of the iParent2Parent Program. Up to 12 peer mentors will be enrolled across two large tertiary pediatric rheumatology centres (SickKids and IWK Health Centre). A total of 40 consenting parents of children diagnosed with JIA will also be enrolled from two large tertiary pediatric rheumatology centres (SickKids and IWK Health Centre) and randomized to the experimental (iParent2Parent Program) (n=20) or control (waitlist) (n=20) group. The decision was made not to recruit at BC Children's Hospital in order to prevent contamination of the sample given the pilot CF-PSP is currently being evaluated in the rheumatology clinic. BC Children's will be recruiting in the future RCT.

Experimental Group. In addition to standard medical care provided to their child, parents in the experimental group will receive online peer mentoring via the iParent2Parent Program. The iParent2Parent program is a tailored peer-mentorship program that provides modeling and reinforcement by peers (trained parents of children with JIA) to parents of children diagnosed with JIA. The program will run over 2-3 months via 5-10 weekly to bi-weekly Skype calls. Drs. Huber and Spiegel will identify 5-7 suitable mentors (male and female) per site who meet eligibility criteria. A member of the research team will interview interested mentors, describe the program, outline requirements, and answer any study-related questions. During mentor training, all mentors will meet with Dr. Ahola Kohut, a licensed psychologist, who will screen for potential psychosocial concerns and considerations when taking on the role of a mentor (e.g., the personal impact of discussing their own child's JIA, speaking with other parents who have a child with JIA). Efforts will be made to pair mentors and mentees who share similar characteristics (e.g., sex/gender) as well as their child's characteristics (e.g., age, diagnosis). During the study period, mentors may be assigned up to 3 mentees at any time. The total number of mentees a peer mentor takes on is their choice. Mentees may be from either SickKids or IWK Health Centre. Before assigning a mentee, the research coordinator will reach out to the peer mentor to discuss additional commitment and assign mentees based on availability and willingness of mentors. A research assistant (RA) at each participating site will facilitate initial Skype calls. Dyads will be responsible for scheduling remaining calls at mutually agreeable times (same time each week with flexibility to schedules). Mentors and mentees may coordinate future calls via Skype or email. If participants cannot complete the iPeer2Peer intervention via Skype (e.g., no access to computer and/or internet), a phone option will be made available for participants to take part in the program.

Parent Mentor Training. Parent mentor training will involve a stepwise approach including both self-directed in-home training and one full day of in-class training facilitated by a psychologist (SAK) and social worker (DE). In-class training will comprise of lectures, active group discussions, small group activities, and role-play activities. iParent2Parent call topics will be decided by the mentor and mentee. However, the training manual will include suggested topics,

advice on structuring conversations, and guides to redirect conversations. Based on the evidence on parent outcomes (6-8), training will emphasize active listening, fostering adaptive coping, and problem-solving skills. Peer mentors will have access to research staff for additional training and support throughout the duration of the study if needed. This includes consultations with research staff and additional training in mentorship skills.

The following study safeguards will be put in place and any adverse events will be tracked:

- Peer mentor training on confidentiality, boundaries, self-care, and when to seek support.
- Peer mentors will be assigned a study specific online account and email address to encourage appropriate boundaries between mentor and mentee.
- Peer mentor training on emergency identification and reporting using a standardized concerns checklist, appropriate services (e.g., 911), and/or the study or local health care team.
- A member of the research team will contact peer mentors at least bi-monthly to ensure mentors are comfortable in their role, not experiencing any undue stress, and to discuss any concerns with the program.
- Dr. Ahola Kohut will be available to facilitate appropriate referrals as necessary via social work department at SickKids and IWK Health Centre.

Control Group. The control group will be on a waitlist and receive usual care without intervention. The iParent2Parent Program will be offered after completion of all outcome measures.

Both Groups. Primary and secondary outcome measures will be collected online from both groups at baseline, 3 months, and 6 months.

Peer Mentors. Prior to mentor training, mentors will complete baseline outcome measures. Immediately following training, mentors will complete training evaluations. At study end, mentors will complete follow-up outcome measures and participate in a focus group.

Procedure:

Following ethics approval, eligible parents will be invited to take part in this study by the clinical care team in the rheumatology clinics at SickKids and IWK Health Centre. Participants may also self-identify to the research team by responding to the study posters or postcards that are in the clinics. A site-specific clinical research project coordinator (CRPC) will obtain consent from interested parents. A member of the research team will track the number of eligible parents approached and if voluntarily provided, reasons for refusal. Subsites will be responsible for consenting mentee participants locally. Once informed consent is obtained, the subsite RA will send mentee contact information to SickKids via secure file transfer. A master database of all participants will be housed at SickKids as we are the central hub and primary point of contact for recruitment and study activity.

Once consent is obtained, baseline demographic and disease-related data will be collected from the child's medical charts and pre-intervention measures will be administered online to parent participants. Online measures for this study will be obtained using REDCap (Research Electronic Data Capture) and housed on a secure server.

Randomization: The CRPC will enter participant ID and stratification variables (i.e., disease activity and study centre) for group allocation into a secure, web-based randomization software (Randomizer). Participants will be randomized 1:1 into one of two groups (iParent2Parent or waitlist), and allocation will remain hidden. The CRPC will then contact participants to inform them of group assignment and instruct them on procedures to be followed.

Proposed Methods for Protecting against Sources of Bias

Blinding. The randomization process will be blinded to site-specific staff and co-investigators to reduce the chance of experimenter bias. Mentors and mentees will be asked not to discuss their study involvement with others until study completion. Mentors and mentees will complete all outcome measures online.

Contamination. To minimize the small potential risk of contamination, participants will be asked about their involvement in other peer support groups, other peer mentors, or any other concomitant interventions.

Outcomes Measures:

- **Primary Outcome:** trial feasibility and acceptability of the iParent2Parent Program. Criteria for feasibility are based on studies previously conducted by our group and will be: accrual rate of >70%, attrition rate of <15%, technical difficulties reported by <10% of parents and mentors, adherence rate of >80%, <5% missed responses on outcome measures and high acceptability (based on qualitative analyses). Data related to the primary outcome will be recorded on investigator-developed forms. Acceptability data will be collected using semi-structured interviews with mentors and mentees at end-of-study.
- **Secondary Outcome:** determination of treatment effect estimates for mentee participants. Effect sizes will be determined for the following: QOL (PROMIS Adult Profile 25 (13), perceived social support (Short form versions of the PROMIS battery for: Social Isolation; Informational Support; and Emotional Support) (13), coping (Coping Health Inventory for Parents (CHIP)(14); and parenting stress (Parental Stress Scale (PSS) (15).
- **Exploratory Outcome:** determination of impact for peer mentors. Effect sizes will be determined for the following: QOL (PROMIS Adult Profile 25) (13), perceived social support (PROMIS Social Isolation; Informational Support; Emotional Support) (13), coping (CHIP) (14), and parenting stress (PSS) (15). Peer mentor perceived benefits and challenges will be collected qualitatively using semi-structured interviews with mentors at end-of-study. Both groups will be asked about additional peer support sought during these time periods.

Statistical Plan:

Feasibility. This project builds on previous and ongoing research conducted by the research team. Our multidisciplinary team comprises of an experienced group of investigators with extensive and collective depth of clinical and research expertise in JIA, parenting chronically ill children, eHealth, QOL, peer support, knowledge translation, qualitative analysis, and mixed methods research.

Sample Size and Recruitment. A total of 20 participants per group is suggested for recruitment in pilot studies to examine intervention feasibility (16). SickKids and IWK Health Centre see over 150 new pediatric JIA diagnoses per year. Using a conservative estimate of 75 children diagnosed in 6 months, with a 30% refusal rate (based on our previous work (17)), we will recruit 40 parents within the timeframe.

Quantitative data will be analyzed using SAS 9.1.3. Baseline sample characteristics will be summarized. Rates of accrual, attrition, adherence, and missing data with 95% confidence intervals will be calculated. To inform sample size calculations for a larger trial, data will be analyzed as a larger trial and estimates of variance and correlation on secondary and exploratory outcome variables will be estimated. If assumptions for parametric statistics are met, linear mixed models will be used to test intervention effects on all outcomes. We will adjust for important factors such as child age, sex, and number of mentoring sessions in our model. Covariance structure will be selected based on model diagnostic statistics. We will examine patterns of missing data, determine demographic and/or clinical characteristics that are related

to missing data at each time point, and the potential impact on the primary findings. The semi-structured mentor and mentee interviews will be audio-recorded and transcribed verbatim. All transcripts will be verified against recordings and imported into NVivo10. Data will be analyzed using an inductive qualitative content analysis approach (18, 19) and used to refine the intervention before a large-scale RCT. This analytic approach was used in previous RCTs and our research team has the required expertise in qualitative analysis (20, 21).

Impact

Expected Results:

This proposal directly impacts an under-researched area of psychosocial and familial health outcomes in pediatric rheumatology. It will result in the development of a new online peer mentoring program for parents of children with JIA. The results of this pilot study will be leveraged in two significant ways: 1) to apply for a large-scale multi-site grant investigating effectiveness and implementation outcomes of the iParent2Parent Program across Canada; and 2) the iParent2Parent Program will be made adaptable to other childhood rheumatic diseases.

Project Deliverables:

This proposal builds from a strong foundation of collaborations and previous experience developing peer mentorship programs for adolescents with JIA (see Preliminary Work section). This project capitalizes on existing research and clinical knowledge to develop a structured program and manual that other pediatric centres can adopt. The iParent2Parent manual will be created as a standalone resource for selection and training peer mentors as well as how to structure the iParent2Parent Program.

Dissemination Plan:

Knowledge translation approaches will include both active and passive strategies in all research stages that involve key stakeholders, including pediatric rheumatology groups (e.g., CAPRI, CARRA), NGOs (Cassie and Friends, The Arthritis Society), lay consumers, clinicians and scientists. Results will be disseminated through key national and international conferences, public affairs and scientific-style newsletters, and publication in leading open-access journals. Findings will also be shared with patients and consumer groups (1-page brochure, media releases [newspaper, magazines, social media such as Twitter], and posting on key websites [e.g., hospitals]).

Feasibility and Sustainability

The sponsor/funder of this research is SickKids and the Canadian Rheumatology Association / Canadian Initiative for Outcomes in Rheumatology Care.

Research Team:

Dr. Ahola Kohut is the lead investigator of this study and is a health clinician scientist and psychologist at SickKids and an Assistant Professor at the University of Toronto. She will oversee every aspect of this trial and its conduct, including day-to-day management of the trial and development of training manuals. **Dr. Stinson**, a clinician scientist and nurse with expertise in mixed methods research, is Dr. Ahola Kohut's career mentor and will support Dr. Ahola Kohut in all aspects of this study for the duration of this grant. **Drs. Huber and Spiegel**, are pediatric rheumatologists and will act as site investigators overseeing site specific screening and recruiting of parent peer mentors and parent mentees and controls for this project. Two investigators from BC Children's Hospital, **Danielle Eccles**, a social worker in rheumatology, and **Dr. Lori Tucker**, a pediatric rheumatologist, will support the development and facilitation of the parent mentor

training and provide expertise related to the CF-PSP. All members will attend meetings to plan and monitor the trial, interpret findings, and write final reports.

Limitations and Identified Alternatives:

Inherent challenges exist when developing a new program, and this has guided our decision to focus on a feasibility RCT. The iParent2Parent Program may not be suitable for all parents of children diagnosed with JIA. Some families in rural communities do not have access to sufficient Internet bandwidth to run Skype. Efforts will be made to adapt the program (e.g., allow phone participation) for all interested parents to participate. The iParent2Parent Program is also time intensive. To accommodate this potential barrier, we have included flexibility in the number of calls between mentors and mentees. There is a potential that mentor-mentee dyads are not well suited for each other. In these cases, we will re-match a mentee with a different mentor. Mentors may also choose to discontinue the program. We will over-recruit a pool of mentors to control for drop out and variability in age, gender and child subtype of JIA. We cannot guarantee our sample will be representative of the whole parent population. However, we are recruiting from two tertiary care pediatric hospitals in ethnically diverse locations that serve both urban and rural populations.

Timeline

The proposed study will be completed within 2 years.

	YEAR 1				YEAR 2			
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
Pre-intervention								
Study set-up	x	x	x	x				
Program adaption	x							
Mentor recruitment				x	x			
Mentor training workshop					x			
Participant recruitment					x	x	x	
Participant data collection					x	x	x	
Intervention								
Participant data collection					x	x	x	
Post-Intervention								
Participant data collection					x	x	x	
Participant interviews/focus groups					x	x	x	
Data analysis							x	x
Control group offered intervention							x	x
Knowledge Translation								
Presentations								x
Final reports & manuscript								x
Research team meetings	x	x	x	x	x	x	x	x

Project Leverages

This project leverages collaborations and phased methodology of the successful development of the iPeer2Peer Program. The iPeer2Peer Program has, based on *patient expressed interest*, already been adopted nationally and internationally (USA: Arthritis Foundation, Ireland: iCAN). The iPeer2Peer Program has also been expanded and is being tested in pediatric samples living with cancer, inflammatory bowel disease, chronic pain, sickle cell disease, and

hemophilia. Parent feedback on the iPeer2Peer Program and requests for a parent adaption have led to this current proposal. Furthermore, this proposal leverages existing relationships with patient run organizations (e.g., Cassie and Friends) and builds from ongoing clinical programming at BC Children's Hospital where a parent peer mentoring program is being formalized and piloted (CF-PSP). The iParent2Parent Program capitalizes on the collaboration, collective and complimentary knowledge, and lessons learned from developing the iPeer2Peer Program and CF-PSP with the aim to develop the most clinically feasible and effective program for parents of children with JIA. The dissemination framework and existing relationships with pediatric rheumatology groups and patient led organizations will also allow for rapid adoption of the iParent2Parent Program should it prove to be feasible and effective.

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